

A black and white photograph of three people, two men and one woman, in a professional setting. They are looking at a laptop screen. The woman is in the center, and the two men are on either side of her.

# THE CENTER FOR INFORMATION & STUDY ON CLINICAL RESEARCH PARTICIPATION



## ABOUT CISCRP

This brochure serves as an overview to CISCRP's many programs, services, and resources designed to inform, educate, and engage the public and patients as partners in clinical research. For more detailed information, please visit [www.CISCRP.org](http://www.CISCRP.org) or call us at 1-877-MED-HERO (1-877-633-4376).

## OUR SERVICES

**Communicating Plain Language Trial Result Summaries** – One of our fastest growing areas and an essential way to recognize the value of patient participation in clinical trials, the CISCRP team works with pharmaceutical and biotechnology companies to prepare and disseminate plain language trial results summaries, informed consent documents, risk management summaries, and ongoing patient communications to study volunteers.

**Patient Advisory Boards** – Another service area in very high demand, CISCRP organizes and facilitates advisory board and panel discussions to solicit and amplify patient voices and perspectives on protocol designs; clinical trial medicine kit designs; informed consent form designs; technology solutions; and patient communication materials.

**Research Services** – CISCRP conducts customized research studies to better understand volunteer perceptions, motivations, and experiences with clinical research. CISCRP has extensive experience conducting secondary research (e.g., literature reviews, landscape assessments) and primary research among patients (e.g., surveys, individual, and group interviews).

**Search Clinical Trials** – CISCRP offers a free concierge-like service designed to help patients, their families, and friends in identifying relevant clinical trials of investigational therapies. CISCRP conducts customized searches and forwards the results along with educational materials for patients to review with their health care providers.

## OUR PROGRAMS

**AWARE for All Clinical Research Education Events** – One of our most established programs- AWARE for All events are conducted in 4 – 6 major cities in the US and Europe each year. These half-day events raise public awareness and appreciation; connect patients with the local clinical research community; and offer interactive exhibits and free health screenings.

**Medical Hero Appreciation 5Ks** – CISCRP organizes and produces 5K run and walk events in major cities to celebrate study volunteers who give the gift of participation in clinical research. CISCRP also organizes and produces 5K events on behalf of individual organizations wishing to encourage their staff to recognize study volunteers as integral partners in clinical research.

**Medical Heroes Campaign** – CISCRP has developed an award-winning public service announcement that recognizes the contribution of clinical trial volunteers. Companies can purchase use of this multi-media (e.g. radio, TV, social media, and print) campaign to raise general clinical research literacy and to supplement their patient recruitment media activity.

**Ambassador Program** – CISCRP has developed a program designed to engage individuals who have completed their participation in a clinical trial. CISCRP offers educational tools and other resources for those wishing to become community ambassadors.

**Medical Heroes Traveling Museum Exhibit** – CISCRP is developing a museum exhibit that will travel to various cities to educate elementary through high school aged children and their families about the clinical research process and the essential role that study volunteers play in the development of new medicines and in improving public health.

## OUR RESOURCES

**Education Center** – Our online education center provides in depth information about clinical research through FAQ's, digital brochures, videos, interactive web pages, articles, and more.

**Facts and Statistics** – Each year CISC RP conducts global studies on public and patient attitudes and perceptions about clinical research. The results of these studies and other statistics about clinical research participation are available on the CISC RP website for download.

**Online Store** – The CISC RP online Store is a great source for educational brochures and videos, Medical Hero posters and buttons, and other items for use and display in company offices, at clinical trial sites, and in health care provider waiting rooms.

**Speaker's Bureau** – CISC RP maintains a global community of professionals and study volunteers available to speak and participate at small and large events, conferences, and in interviews with journalists and reporters.

## GET INVOLVED

**Sponsorship Opportunities** – Sponsor an AWARE for All event, Medical Hero Appreciation 5K, development of new educational brochures or videos, a Medical Hero Thank You newspaper supplement, or talk to us about other sponsorship opportunities.

**Donate** – All of our patient and public education programs are fueled by generous donations that we receive from our supporters. You can donate online at [www.ciscrp.org](http://www.ciscrp.org), by check made out to CISC RP and sent to One Liberty Square, Suite 510, Boston, MA 02109, or by phone at 1-866-633-4376.

**Volunteer** – Donate your time at a local AWARE for All event or Medical Hero Appreciation 5K Run/Walk, or participate in a survey, in our speakers bureau, or on one of our advisory panels.

**Support** – We are always looking for creative ways to collaborate; from assistance with outreach including social media event blasts, to donating pro-bono skills or expertise.

**Subscribe** – Join our community to receive email notices about our events, our newsletter, educational materials, free resources, and much more.

### Contact Us

✉ [info@ciscrp.org](mailto:info@ciscrp.org)

☎ 1-877-633-4376

### Follow Us

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AWAREforAll



Clinical Trial  
RESULTS



EDUCATION  
before  
PARTICIPATION

Search Clinical Trials 🔍

**Jim Kremidas**  
**Executive Director**  
**Association of Clinical Research Professionals**

Jim Kremidas is currently the Executive Director for the Association of Clinical Research Professionals, a not-for profit association that represents the clinical research enterprise. Prior to that he conducted consulting services for a variety of clients including support for investigator sites, academic institutions, sponsors and suppliers. Mr. Kremidas was the Senior Vice President of Patient Recruitment at two different large Contract Research Organizations (CROs) for over six years where he and his team were responsible for developing and implementing patient enrollment strategies for global clinical trials.

Mr. Kremidas spent 24 years with Eli Lilly and Company. From 1999 to 2008, he led their clinical trial patient recruitment and retention efforts. In this role, he focused on predicting and accelerating the enrollment rates for all corporate studies. While in clinical development strategic sourcing, Jim was responsible for the outsourcing of clinical development projects to strategic suppliers including CRO's, scientific staffing firms and patient recruitment suppliers. In addition, Mr. Kremidas led Lilly's efforts to select and establish relationships with direct to consumer and professional advertising agencies, as well as implement standardized processes for the development and implementation of marketing materials.

Mr. Kremidas is on the advisory board of Center for Information and Study on Clinical Research Participation (a non-profit organization focused on enhancing patient participation in clinical trials) and is also a volunteer for the Clinical Trial Transformation Initiative with Duke and the NIH. He is a frequent presenter at Industry Conferences and his articles/papers have been published in a wide variety of trade journals.

# Association of Clinical Research Professionals

## About ACRP

### ***NON-PROFIT, MISSION-FOCUSED***

**Mission: ACRP Promotes Excellence in Clinical Research**

**Vision: Clinical Research is Performed Ethically, Responsibly, Professionally Everywhere in the World**

- 13,000+ Individual Members in 70+ Countries
- Registered 501(c)(3) Organization Based in Washington, DC
- Founded in 1976

**32,000+ ACRP CERTIFIED PROFESSIONALS**

- Principle Investigators
- Study Coordinators
- Site Monitors

Novartis Oncology

## Novartis in Cancer:

Reimagining Medicine by Transforming Cancer Care

There were 14 million new cases of cancer worldwide in 2012; the World Health Organization believes this figure will rise 70% by 2032<sup>1</sup>



Our mission is to discover new ways to improve and extend people's lives.



**Ranked #2** oncology company in the world<sup>2</sup>



**15+ year** focus on cancer

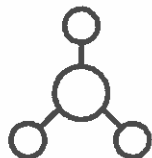


Presence in **80+ countries**

We use science-based innovation to address some of society's most challenging healthcare issues.

### Focused R&D Strategy:

Our strategy is to leverage our leadership in targeted therapies (TT) and our strong immuno-oncology (IO) platform to build depth in five priority areas by developing combinations (TT +IO and IO+IO) that improve outcomes for patients.



**30+** new oncology molecules in development at Novartis

**18** immuno-oncology compounds being explored

**19** targeted therapies in confirmatory development

**180+** active clinical trials

**45,000+** patients currently or soon-to-be enrolled in clinical trials

We discover and develop breakthrough treatments...



**20+** medicines for oncology, hematology and rare diseases



Treating **25+** conditions



**12** regulatory approvals worldwide and **9** pivotal trial read-outs in 2016

...And find new ways to deliver them to as many people as possible.

**85,000+**

patients reached through Novartis Oncology access programs

**600+**

patient organization relationships across the world



**Tracy Baroni Allmon BS Pharm., J.D.**  
**Executive Director, Health Policy**  
**Novartis Oncology**

Tracy Baroni Allmon has a B.S. in Pharmacy from Duquesne University in Pittsburgh, and a law degree from University of Baltimore. Following graduation from law school, Baroni Allmon worked for the Maryland Board of Pharmacy as their Compliance Officer.

Since then she has held policy positions within various health care segments, including chain drug stores, pharmacy benefit management, and the pharmaceutical manufacturing sector.

Baroni Allmon's addition to Novartis came in December 2009, when she accepted the re-vamped Executive Director of Oncology Health Policy position. In her current position, she is responsible for reviewing and developing positions on proposed laws and regulations, coordinating business activities and responses to proposals, informing the business of future threats and opportunities, and strategy development.

She leads a team of three state-focused policy and advocacy professionals. Her office is in Washington D.C., and she is responsible for Novartis policy relationships with several patient and professional groups there, as well.



American Cancer Society  
Cancer Action Network  
1755 Abbey Road  
East Lansing, MI 48823  
517.332.2222  
[www.acscan.org](http://www.acscan.org)

**Volunteer Name:** Madison Horton

**Organization:** American Cancer Society Cancer Action Network (ACS CAN)

**Age:** (17)

**Address:** Saint Clair Shores, MI

**County:** Macomb

Madison Horton is a 17-year-old cancer survivor from Saint Clair Shores. On January 7th of 2016, she was diagnosed with melanoma and had to undergo a major operation on her back and under both arms. Every 3 months she sees a melanoma specialist to monitor her cancer. Since her first surgery she has undergone many biopsies, a few which resulted in further surgeries. Because of her cancer experience she would like to provide services and support to patients, providing them with the excellent care they deserve. She's working with the American Cancer Society Cancer Action Network to further benefit the community.

### *Madison Horton*

On January 7th of 2016 I was officially diagnosed with spindled neurotropic melanocytic proliferation, a cancer very uncommon in young women. This was a shock to my family and I, as I am adopted from a small city in Russia. My journey began when I had a mole removed around Christmas time the prior year. When the results came back, I had to undergo a major surgery that was scheduled to be two and half hours but ended up lasting six hours due to complications. I was cut on my neck, under both arm, and on my back. Since this, I now see a melanoma specialist about every three months and continue to have minor surgeries. Being diagnosed with skin cancer at such a young age has forced me to make changes throughout my everyday lifestyle and be more concerned with protecting myself from the common risk.

Melanoma is a type of cancer that people can be diagnosed with in many different ways. As for me, it was unexpected and the source is hard to declare being that I am adopted and was not provided with any medical history from my birth family. However, many people are unaware of the everyday dangers that put people at risk to containing this disease. While this disease is not uncommon for people to obtain over time, it is easy to prevent the exposure to the presented everyday risk. A main source of melanoma is over-exposure of the sun. The harmful rays damage skin effortlessly. In today's society, and being a high school student, many young people do not have concern for the damage the sun can cause to health. A prime example of this is in the summer when my friends do not apply sunscreen, or go to tanning salon's before homecoming dances due to the need to have "tan skin". As this is one of the many risk of melanoma, there are many others that are just as significant and easy to prevent.

*Laura Horton*

Before the word “cancer” came into my daughter and my’s life, I took her to see a dermatologist for acne. This developed into the doctor seeing the need for removal of a small mole located on my daughter’s back that I perceived to be a birthmark her whole life. The results of this came back both negative and positive for cancer, needing further review and testing by another pathologist. After the holidays were over, the results came back to be a very specific type of melanoma requiring immediate treatment. Between January 7th and February 2nd, my daughter had to undergo multiple test. The most difficult test to see my daughter go through as a parent was a type of radioactive dye test that displayed the path the cancer was spreading throughout her body, signifying to the doctors which lymph nodes to remove. It was overwhelming to watch a blank screen so quickly light up in all types of colors. The longest day of it all was the day of her main surgery, which felt like it had lasted forever. As a parent of a child with a rare cancer, I realized how much of a concern little marks on a body can be to someone's health.

With many parents in the world who have a child suffering from cancer, it is our duty to protect our children from any forms of danger. My daughter’s skin cancer is a type of cancer that can be received genetically but can also develop inside someone over time without genetic influence. Thus, it is of high significance to prevent something to the extent in which our control can work with. No parent should have to experience their child containing a deadly disease. Many precautions and adjustments can be made to prevent an individual from exposures and risks to skin cancer specifically. Not only will preventable actions look out for the youth, but for all individuals who are exposed to risks that can be encountered everyday. Being one of the worst ordeals in my life, I will do whatever it takes to prevent this from happening again.